Euro-CASE Annual Conference 2016

Midday Session: Big Data Changing Health Care

| **Hosts** | ATV – Danish Academy of Technical Sciences |
| | DTU – Technical University of Denmark |

| **Date** | Monday 14 November 2016 |

| **Venue** | **Meeting Room S01, ground floor, DTU** |

Big Data Changing Health Care

Health care costs are forecasted to increase dramatically in the coming decade as a result of an aging population in Europa and as a result of an increasing availability of novel innovative, but often costly, opportunities for treatment.

The use of Big data solutions in health care may help keeping health care costs under control by targeting treatment more towards the individual and by facilitating quality assurance across the treatment journey. By combining multimodal data on e.g. personal health parameters, behavioral parameters, biomarkers etc. across thousands of individuals, big data analytics and modelling may indeed enable application of today's health technology for a more personalized treatment with higher efficacy. Similarly, by combining data on treatment actions throughout the treatment journey with clinical- or self-assessed outcome data across thousands of patients, big data modelling enables data driven efficacy assessment of different treatment modalities, thereby facilitating data driven quality assurance in health care systems.

While big data holds a promise for keeping health care costs under control and for higher efficacy through personalized treatment, there are a number of aspect concerning health care data privacy that needs to be observed – both from a legal and an ethics perspective.

In this session, opportunities for changing health care by use of big data analytics and modelling will be discussed along with aspects of data privacy and ethics in big data based health care solutions.

About the speakers:

Søren Brunak is professor of Disease Systems Biology at the University of Copenhagen Medical School and professor of Bioinformatics at the Technical University of Denmark. He has been a pioneer within the general areas of bioinformatics and computational biology and has been active in these fields from the mid-80ies and onwards. His focus has in particular been the machine learning angle. He co-authored the first text book in the area, "Bioinformatics: The Machine learning approach", MIT Press 1998 (with Pierre Baldi). Today his research groups combine molecular level systems biology data with the analysis of clinical data, in particular electronic patient records, nation-wide registry information and biobank questionnaires. He studies the temporal order of comorbidities; "disease trajectories", including treatment provoked disease correlations and how to stratify patients not only from their genotype, but also phenotypically based on clinical descriptions in their medical records. An additional focus area is human proteome variation in the context of precision medicine.

Anders Quitzau is Innovation Executive and Watson Advocate in IBM Denmark, working cross industries with public as well as private companies to explore the value of emerging technologies and concepts. This is very often in collaboration with IBM Research and IBMs global development lab's and Centers of Competence around the world.

Peter Nordqvist is head of Hörselbron. Hörselbron is an independent research institute within audiology. He has a long experience of research within hearing aids. Hörselbron is now responsible for a national data collection within the hearing health care system in Sweden. Peter has a strong believe in big data solutions for improving health care. He has a PhD in hearing technology from Royal University of Sweden.

Kerina Jones is an Associate Professor of Health Informatics at Swansea University Medical School. She has led on the development of successful bids to establish Big Data centres and to secure research grants, and is the academic lead for information governance initiatives to ensure data protection and maximise data utility. Kerina is part of the senior management team of the Secure Anonymised Information Linkage (SAIL) system, she is a co-investigator on the Administrative Data Research Centre (ADRC), and on CIPHER: the Centre for the Improvement of Population Health through E-records Research, which is part of the Farr Institute for Health Informatics Research. She leads an Innovative Governance working group for Farr and she established a thriving Consumer Panel for data linkage research.

Kerina is involved with many projects that bring together disparate sources of data to enhance research and enable new types of studies to be conducted. She has a keen interest in the development of innovative disease registers, notably the flagship UK Multiple Sclerosis Register which brings together a wealth of patient-reported, clinical and routine data to create new knowledge about living with MS. With an academic background in Biochemistry, she is particularly interested in projects where 'omic data can be linked to routinely-collected health-related records to create rich datasets for research.

Nathan Lea is a Senior Research Associate at the UCL Institute of Health Informatics (IHI) working on projects in clinical care and research. His research interests include the role of information systems in supporting healthcare delivery and empowering patients, and Information Governance in the use of genetic, health and social care records in clinical research, particularly in the age of Information and Big Data.

Nathan works on the Information Law and Governance In Clinical Practice and eHealth modules of the IHI's Health Informatics MSc and courses in UCL's MBBS. He has co-developed and deployed clinical information systems used at Whittington Health for Cardiovascular care and Dementia registries with the West London Mental Health Trust and UCL's Dementia Research Centre.

Nathan works with the Farr Institute of Health Informatics Research and is a member of the Innovative Governance Group. He sits on the UCL's Security Working Group and Athena SWAN Self-Assessment Team.

13:50	**Welcome and setting the scene**
	Moderator Søren Riis, Senior Director, Technology Development, Oticon Medical

13:55	**Linking two temporal big data domains: the clinical and the omics worlds**
	Søren Brunak, Professor, Research Director, Novo Nordisk Foundation Center for Protein Research

Health data are per definition temporal and essentially all data types are tagged with timestamps. This holds true for data from the clinical domain, diagnoses, procedures, prescriptions, patient record text, or various types of monitoration data, but for the molecular domain this is equally true, independent of whether the latter represent conventional blood test data or high volume omics data such as those from DNA or RNA sequencing or clinical proteomics. Time scales varies enormously. The talk will discuss the data integration challenges in this highly heterogeneous area and give examples in the context of lifelong disease modeling and patient stratification.

14:15	**The next healthcare revolution comes from data**
	Anders Quitzau, Innovation Executive, IBM (Watson)

Technology and cognitive computing is transforming wellness and healthcare. When machines are capable of understanding the language of medicine and biology, and being able to process the exponentially growing volumes of knowledge and health data, totally new pathways of prevention, treatment and care are made possible. This is the opportunity that IBM Watson Healthcare is targeting.

14:35	**Quality assurance in health care based on Big Data**
	Dr. Peter Nordqvist, Managing Director, PhD Forskning-sinstitutet Hörselbron

Collecting data from the health care system is a unique possibility for improving quality of health care, understanding what factors that makes a difference for the patient, and improving assistive products.

The Swedish Quality Register within Hearing Rehabilitation collects information both from private and the county organized dispensers. The register includes subjective and objective information. The objective information is transferred directly from the journal system and consists of clinic, audiologist, audiogram, manufacture, and hearing aid model. The subjective information consists of a self-reporting questionnaire collected from the patient six months after the rehabilitation. The measures in the questionnaire comprise the international outcome inventory for hearing aids (IOI-HA; Cox & Alexander, 2002), a set of questions regarding satisfaction with specific features of the hearing aid, and clinical service (information, participation, and treatment). The information is collected in an identical way for all patients in order to minimize bias effects. Each year the register collects data from about 50,000 prescriptions. The data is structured on a national level, a county level, a dispenser level and an individual level.

14:55	**Striking the balance between data privacy and data use**
	Kerina Jones, Associate Professor Swansea University

Data collected about individuals in the course of healthcare delivery have immense value for research and evaluation. But there are challenges to be overcome in order to strike an appropriate balance that respects individual privacy and maximizes data

utility. Data safe havens, where anonymized versions of health-related datasets are held in a secure environment, are an approach being used in Big Data applications to address the challenges.

This talk will describe the Secure Anonymised Information Linkage (SAIL) data-bank and the UK Secure Research Platform (UKSeRP) as examples of data safe ha-vens, with their operating models for health data privacy and data governance. It will touch upon: current and emerging types of health data; the regulatory landscape and debate; engaging with the public; example health data privacy projects, and the work of the Innovative Governance Working Group of the Farr Institute for Health

Research in promoting safe data access and sharing. It will use these topics to show how the challenges are being addressed to move forward with practical solutions.

15.15	**Risk and reward - why Big Data needn't be a big problem for privacy** *Nathan Lea, Senior Research Associate at the UCL Institute of Health Informatics (IHI)* The practice of medicine has been evolving rapidly over the last twenty years, thanks in part to the rapid uptake of digital interventions that support a meaningful shared care journey for practitioners and patients. The arrival of cloud based ser-vices and promise of Big Data driven research is a tantalizing prospect for continu-ing this trend, but to what extent is the technology driven evolution destabilizing our confidence in privacy and confidentiality? This talk examines the risks involved with this evolution with a view to informing a discussion about the importance of supporting trust in the confidential therapeutic relationship and understanding the significance of Big Data in the care context.

15.35	**Panel debate**
	   – *Søren Brunak*
	   – *Anders Quitzau*
	   – *Peter Nordqvist*
	   – *Kerina Jones*
	   – *Nathan Lea*

15:55	**Summing up** *Rasmus Larsen, Professor, Head of Department, DTU Compute*
16:00	**Return to main hall "Glassalen" on ground floor**